

with Shy Bladder Syndrome (paruresis)?

This guidance is for the person who believes that they may have paruresis, anyone supporting them, and their GP.

It has been compiled with guidance from the following:

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## Does my patient have paruresis and if so what can I do about it?

Paruresis is an inability for individuals to urinate in the presence, real or perceived, of other people. It causes them to avoid situations that may make it difficult or impossible for them to be able to urinate. It affects both men and women of all ages and backgrounds, with up to 7% of the adult population experiencing it to some extent.

This guidance aims to answer some questions you may have if you're not familiar with paruresis, and addresses some commonly observed misconceptions.

Paruresis, aka Psychogenic Urinary Retention, is classified as a Social Anxiety Disorder in the Diagnostic and Statistical Manual (DSM V) of the American Psychiatric Association.

A defining characteristic in the diagnosis of paruresis concerns the context of its occurrence. If the individual can urinate normally in self-defined safe situations but finds it difficult in other situations that have a social element, then it is highly likely to be paruresis.

Many who consult their GP with paruresis have not discussed their condition with a professional before and may not even have disclosed it previously. See "What your patient is thinking" in the British Medical Journal October 2021

https://www.bmj.com/content/375/bmj.n2197

## **Interventions**

This guidance follows the National Institute for Health and Care Excellence (NICE) recommendations for social anxiety disorder.

For severe cases that struggle in every situation, the UK Paruresis Trust (UKPT) suggests that it is advisable to be seen by a urologist to rule out any potential physiological or physical impediments to successful urination. If found, once they have been resolved, the individual may then be able to urinate freely in all or most situations. Note that if there have been physical restrictions, a chronic experience of difficult urination could result in the individual developing paruresis for which Cognitive Behavioural Therapy (CBT) may still be required.

If it is clear that there are no underlying physical conditions affecting the shy bladder, then a referral to the local Improving Access to Psychological Therapies (IAPT) team for CBT or to a clinical psychologist may be useful, especially if the practitioner has experience with paruresis. In any case, it is highly recommended that the patient be encouraged to make contact with the UKPT, whose support and workshops have a high success rate (see workshop evaluation study

https://www.ukpt.org.uk/images/UKPT-Workshop-Feedback-Evaluation-Report.pdf)

"This is the perfect environment to start working on our condition. There is a mixture of theory and personalised exercises. While the leaders are not medical professionals, they have plenty of experience, knowledge and interest in the topic. The methods we learnt seem applicable to real life situations.

What I particularly liked was honesty and emphasis on real progress, achievable goals and preparation for setbacks." The UKPT doesn't offer clinical treatment but its information services and self-help based workshops have been a helpful resource for more than 1000 individuals with paruresis since 2003. Research has shown that a workshop run by the UKPT could result in a 95+% increase in knowledge and understanding of paruresis and how to develop effective coping strategies. Furthermore, many people who attend a workshop have never spoken to anyone about their paruresis so the opportunity to talk to other people about shared experiences can be liberating and empowering.

Feedback includes comments such as:

"The workshops show you that there is a way to improve the severity of a shy bladder and they provide you with all of the knowledge that you need to go about improving your life. Anyone who wants to get better should sign up - there is nothing but positives to be gained from attending."

"My progress definitely surpassed all my expectations.... I'm way more optimistic about my recovery....now I know that I can overcome it, that's a big relief"

We would therefore strongly suggest that whatever professional referrals are made, signposting someone with paruresis to the UKPT website with the recommendation that they consider attending a workshop has a high probability of being immensely helpful for them.

## Common misunderstandings

Once the bladder is full the individual will have no choice except to urinate	Urinary retention by someone with paruresis is absolute: the effect of the autonomous nervous system being to relax the detrusor and close the internal sphincter, hence however full the bladder, the sphincter will stay closed. Contrary to popular perception, it cannot be consciously overridden and even a painfully full bladder will not empty.
If you just relax you will be able to urinate	The rest of your body may be very relaxed, but this will not be sufficient if the bladder muscle is slack and the urethral sphincter is locked tight.
Paruresis is not a disability	According to the Income Data Services Handbook on Disability Discrimination, a severe case of paruresis may meet the criteria of "a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities".
Catheterisation is not a suitable treatment option	Intermittent self-catheterisation (ISC) can enable some patients to gain control of their bladder, rather than their bladder controlling them https://www.ukpt.org.uk/media/attachments/2021/01/26/from-the-professional-nurse-magazine3.pdf The resulting reduction in anxiety can enable an individual to engage in normal daily life activities, including undertaking a therapeutic process of CBT. Again, contrary to popular perception, ISC by males shows a very low to nil incidence of infection. Unfortunately, for obvious reasons, infection rate among women is more prevalent.

Thank you for reading this information.

By referring your patient for specialist assessment and treatment for their paruresis, you will be giving them the best chance of overcoming this life-affecting problem.

By additionally signposting your patient to the UKPT website, you will be offering them the opportunity to access support and help from people with lived experience of beating paruresis.

General enquiries? Looking for support? Visit www.ukpt.org.uk for information about paruresis, including CBT based workshops. Or you can email us at info@ukpt.org.uk if you have a specific query.

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Sources used to create this information resource are available by contacting the UKPT.

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